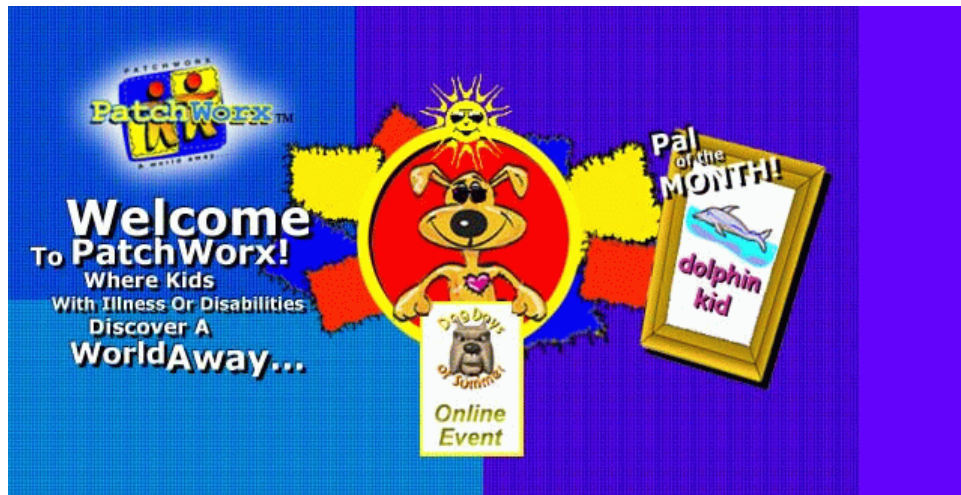


PatchWorx: A Circle of Support Across America

by
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Someday technology may solve, or seriously reduce, the problem of disability. Maybe. But, in the meantime, people suffer more than simply physical discomfort from disability or critical illness. There's an emotional and spiritual pain that comes from the isolation, the lack of social contact, that comes from being hospital- or home-bound. A number of TOP-supported projects have employed information technology to help alleviate the feeling of isolation that critically ill or seriously disabled people experience. Most recently, PatchWorx in San Mateo, California, has created an online **Circle of Support Across America** to serve the more than half a million children in the United States between the ages of 5 and 18 who suffer from critical illness or a serious disability.

Over and over, hospital- or home-bound children say that the only ones who really understand what they are going through are other youngsters facing similar challenges. The PatchWorx project enables children to reach each other across the barriers of distance and disability, helps them develop coping skills, and shows them how to find the kind of information that can turn them into "proactive patients."

The Circle of Support web community is strengthened by partnerships with Ronald McDonald Houses in Stanford, California, and Burlington, Vermont; hospitals in Tennessee and New York; and schools around the country. These institutions identify children, facilitate parental permission, monitor participation, and help recruit adult volunteers. One of the principal partners is the National Cristina Foundation (a TOP grantee in 1995), which provides refurbished computers and other equipment to children. Over the course of the project, PatchWorx will serve more than 400 members and a larger number of non-member users, develop effective methods of recruiting and retaining online volunteers, and formulate a model for providing a national community for children with critical illnesses or disabilities.

The Circle of Support integrates well with existing technology programs for hospital-bound children. In February, 2003, Children at Vanderbilt Children's Hospital were able to log onto the PatchWorx network through the hospital's "[Go Fetch](#)" program, which provides children with access to computer workstations on specially designed carts that adjust and accommodate patients at every stage of treatment and recovery. Video cameras on each computer allow children to videoconference, or allow their parents to monitor their children from home or work.

Along with the obvious benefits of a project like this, there are also some questions that need to be asked. For example, how can the Circle of Support contribute to the ongoing discussion in the research community about the effects on children of time spent in virtual environments? This project can address this question and, in the process, teach us a great deal about how working in a virtual environment supports or interferes with a child's life in the real world. We may begin to see, for example, that children in the project 'graduate' from PatchWorx because they now have coping skills they didn't have before, including the ability more easily to relate to the real world. This may be one of the most intriguing lessons to be learned.